

Submitter: Oriana Horneck

On Behalf
Of:

Committee: Joint Committee On Ways and Means Subcommittee On Human
Services

Measure: HB5026

Co-Chair Campos, Co-Chair Valderrama, and Members of the Committee,

My name is Oriana Horneck and I am in support of HB 5026 to fully fund ODDS, and to consider funding beyond this due to the additional bills being considered this legislative session (SB 91 & SB 646) that would impact the budget. I watched the hearing that took place over the past couple of days and I would like to speak to the discussion around cost and funding for the two current senate bills for paid parent caregivers. I am the mother of a 7-year-old boy who has multiple severe disabilities that require him to have around the clock care at home.

First, you need to understand that the amount of attendant care hours our children receive has already been determined by ODDS through the Child Needs Assessment (CNA). These hours represent the amount of care our children need BEYOND their typical peers because developmentally and cognitively they are behind, and they additionally often require significant medical care and attention. These hours can be used to hire support workers, however, for many reasons, families cannot fill these hours and/or they do not want someone in their home for that many hours a day. The hours are already provided to these kids so they can live at home. All we are asking for as parents, is to have the option to fill that job ourselves if we feel it is best for our child.

I appreciated Senator Gelser Blouin sharing her personal experience, but I want you to know that my lived experience is different and speaks to the spectrum of caregiving needs I/DD children have. Bathing and dressing is part of my son's caregiver support, but that is just a sliver. He requires constant monitoring for seizures and secretion management. He requires someone to assist him for every part of every day. He has no voluntary control over his body and therefore cannot bring anything to him and cannot move from one position to another. Additionally, he needs continuous nighttime monitoring due to his risk of seizures and aspiration. I am up all night caring for him to keep him safe and healthy. I do it because I am his mother and I love him. But it is a job. The caregiving support he needs is not parenting. A typical 7-year-old is sleeping alone, dressing themselves, feeding themselves, and entertaining themselves. Their parents get to bathe them, or play with them, or eat with them. Because of my son's high level of care, there is little time for parenting. Most time is spent caring for his needs. But I do it, paid or not for these caregiving duties, because that is one of the main ways I can interact with him.

Finally, if cost for this program is an issue, please consider SB 91 with amendments to some of the many restrictions. This bill will cost less as it limits the number of eligible children, but it still allows kids with the highest needs to have their parents as a caregiver if the family chooses.

Sincerely,
Oriana Horneck